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Addendum to the Iowa State Profile Tool: An Assessment of Iowa's Long-Term Support System

Submitted September 24, 2010

To Ro Foege
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The Iowa State Profile Tool is a comprehensive, high-level assessment of Iowa's progress toward a balanced long-term care[1] system – a system that relies less on institutional services and provides greater opportunities for the in-home and community-based services that most people prefer. The Iowa State Profile Tool includes information about long-term support for people of all ages and disability types and is based on a variety of state and federal data sources and interviews with public and private leaders in Iowa's long-term care system. The Iowa Department on Aging (IDA) released the Iowa State Profile Tool in April 2009, and it is available at http://www.aging.iowa.gov/Documents/SPT_FinalReport.pdf.

The Iowa State Profile Tool was developed under a grant from the U.S. Centers for Medicare & Medicaid Services awarded in September 2007. As part of this grant, IDA requested three additional sections focused on long-term support topics of particular importance:

1. Informal caregivers, family members and friends who provide most long-term support on a volunteer basis
2. Direct care workers, staff who provide paid long-term support
3. Services for people with Alzheimer's disease and related dementias

Each section is inclusive of all people who need long-term support, to the degree possible. The first two sections present information related to those who provide assistance to individuals who need long-term support regardless of age, including both children and adults. The third section describes a set of conditions that primarily affect older adults, although it includes data regarding early onset dementia.

For each section, this addendum presents four types of information:

- Prevalence data – state and/or national data regarding the number of people who are informal caregivers, who are direct care workers, and who have dementia
- Characteristics data – additional information regarding these individuals that can inform Iowa's policy community
- Challenges – information regarding the challenges faced by informal caregivers, direct care workers, and people with dementia
- Iowa initiatives – current and recently completed efforts to address the challenges

[1] We use the phrases "long-term care" and "long-term support" interchangeably and use a definition developed by the Georgetown University Long-Term Care Financing Project: "Assistance with essential, routine tasks of life – such as bathing, getting around the house, and preparing meals – provided to people who need this assistance because of physical or mental conditions or disability." This assistance can include therapies or equipment to improve a person's functional capacity. (Rogers, Susan and Komisar, Harriet "Who Needs Long-Term Care?" Georgetown University Long-Term Care Financing Project: May 2003)

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Addendum to the Iowa State Profile Tool:
Section 1: Informal Caregivers

Informal caregivers are "unpaid individuals such as family members, friends, or neighbors who provide care." They can be "primary or secondary caregivers, full or part time, and can live with the person being cared for or live separately."[1] Informal caregivers provide most of the long-term support provided for people with disabilities and older adults. This section presents information on the number of informal caregivers in the United States and in Iowa, and describes characteristics of informal caregivers and challenges these caregivers often face. The section concludes with a summary of Iowa initiatives that provide support for informal caregivers.

Prevalence of Informal Caregivers

A 2009 report by the National Alliance for Caregiving and AARP estimated 65.7 million American adults age 18 or older (28.5% of all adults) were unpaid caregivers for adults with disabilities or children with special health care needs at some point in the past year. Approximately 46 million adults (20% of all adults) were caregivers at the time of the survey.[2] AARP estimated that 450,000 Iowans provided informal care for adults age 18 years or older during 2007.[3] This number was roughly 20% of the adult population for that year,[4] but only includes caregivers for adults. State-level data for caregivers for children are not available.

Informal Caregiver Characteristics

A national survey of adults age 18 and older by the National Alliance for Caregiving and AARP provides valuable information regarding informal caregivers. We use findings from this survey to describe several characteristics of informal caregivers.[5] The survey sample size was not large enough to produce reliable state-level data, and we are not aware of other sources for similar information regarding Iowa's informal caregivers.

Relationship to Person Receiving Support

Most caregivers in 2009 assisted a relative by blood or marriage (86%). The most common caregiving relationships were supporting one's parent (36%) and one's child (14%).[6]

Use of Paid Services

In 2009, a majority of caregivers helped a person who received no publicly or privately funded services (59%). Almost 30% of caregivers supported a person living in a private home who received paid services. The remaining caregivers helped someone living in a

[1] Family Caregiver Alliance, Selected Caregiver Statistics, revised 2005
[2] National Alliance for Caregiving and AARP *Caregiving in the U.S. 2009* November 2009
[3] AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving*, *2008 update*, November 2008
[4] Thomson Reuters analysis based on data from AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving*, *2008 update*, November 2008 and U.S. Census Bureau "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2008" May 14, 2009
[5] National Alliance for Caregiving and AARP *Caregiving in the U.S. 2009* November 2009.
[6] *Ibid.*

residential setting such as a nursing facility, assisted living facility, or a retirement community (12%).[7]

Age

Most caregivers were between the ages of 35 and 64 in 2009 (64%). By comparison, most people receiving support were age 50 or older (72%). Almost half people who received informal care were age 75 or older (44%).[8]

Gender

Two-thirds of caregivers in 2009 were women (66%). In addition, most people receiving support were women (62%). There was little gender difference among people under age 50 receiving informal support, but 68% of informal care recipients age 50 or older were women.[9]

Employment

A majority of 2009 caregivers were employed at the time of the survey (57%). A larger percentage of caregivers were employed at some point during his or her time as a caregiver (73%).[10]

Number of Care Recipients

One-third of caregivers reported caring for more than one person in 2009 (34%). This included 20% of caregivers who said they supported both an adult and a child with special health care needs.[11]

Duration of Caregiving

In 2009, caregivers had provided care for an average of 4.6 years. The duration of caregiving varied. Approximately one-third of caregivers had provided care for less than one year. Another one-third had provided care for one to four years, and the final third had provided care for five or more years (See Chart 1.1).[12]

[7] *Ibid.*
[8] *Ibid.*
[9] *Ibid.*
[10] *Ibid.*
[11] *Ibid.*
[12] *Ibid.*

Addendum to the Iowa State Profile Tool:
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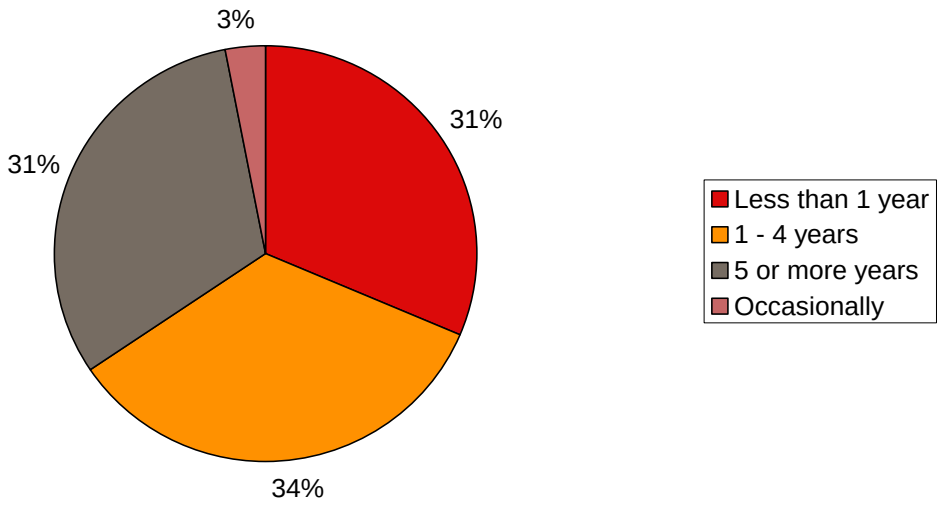
Chart 1.1: Distribution of Informal Caregivers by Duration of Caregiving



The sum of percentages is not 100% due to rounding. "Occasionally" means the person provided care on an intermittent basis, such as providing respite to a primary caregiver.

Source: National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2009*, November 2009

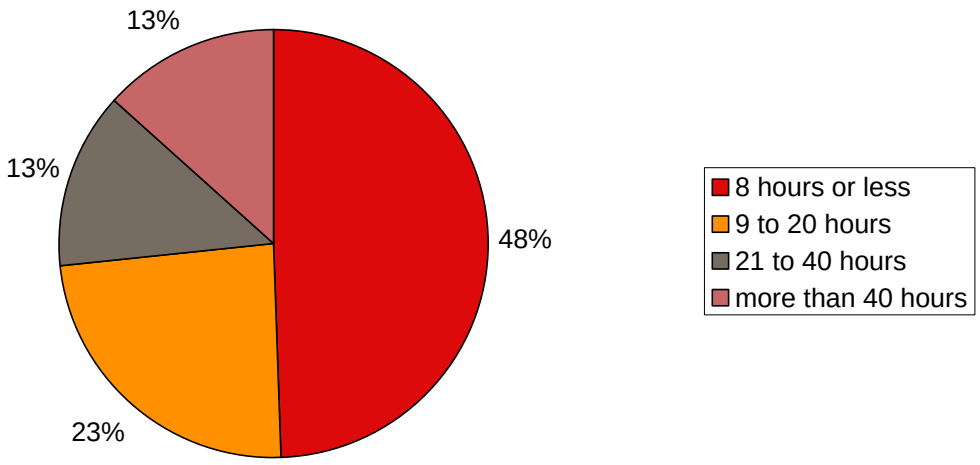
Hours of Care Provided

Informal caregivers spent an average of 20.4 hours a week providing care in 2009.[13] The amount of time caregivers spent varied widely depending on the needs of the person receiving support, the availability of other caregivers, and any paid services the person received (See Chart 1.2).

[13] *Ibid.*

Addendum to the Iowa State Profile Tool: Section 1: Informal Caregivers

Chart 1.2: Distribution of Informal Caregivers by Hours of Caregiving Per Week



Source: National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2009*, November 2009

Economic Value of Informal Care

AARP developed an estimate of the economic value of caregiving for adults in 2007 based on data on the number of caregivers, the number of hours of support provided, and the hourly value of the care. This estimate was 80% greater than total formal long-term care expenditures in 2005, the most recent year for which data are available.[14] Table 1.1 compares the economic value of caregiving for adults to Medicaid long-term care expenditures data for both Iowa and the nation. These estimates do not include support for children with special health care needs, for which data are not available.

Table 1.1: Economic Value of Caregiving in Comparison to Medicaid Long-Term Care Spending, 2007

	Caregiving for Adults	Medicaid LTC Spending
Iowa	$3.4 billion	$1.2 billion
United States	$375 billion	$104 billion

Sources:
AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, November 2008 and Burwell, Brian, Sredl, Kate and Eiken, Steve, *Medicaid Long Term Care Expenditures FY 2009*, August 17, 2010

[14] AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, November 2008 and Komisar, Harriet and Thompson, Lee "National Spending for Long-Term Care" Georgetown University Long-Term Care Financing Project February 2007

Addendum to the Iowa State Profile Tool: Section 1: Informal Caregivers

Challenges for Caregivers

Many caregivers experienced a high level of stress and poor health as a result of caregiving. Some also reported financial difficulties, particularly when caring for children. Since a majority of caregivers were employed, caregiving also had a financial effect on the businesses where they worked. In addition, most caregivers reported a desire for more information on a variety of topics.

Stress

Almost one-third of informal caregivers considered their caregiving situation highly stressful (31%). Caregivers who provided more hours of care per week, and who did not perceive they had a choice in becoming a caregiver, were more likely to report high stress.[15]

Health

One of every six informal caregivers described their health as fair or poor (17%), compared to 13% of the general adult population. The percent of caregivers reporting fair or poor health increased with the length of time providing care; 23% of people who had provided support for five or more years reported fair or poor health.[16]

Caregiver Financial Hardship

Most caregivers in 2009 reported little or no financial hardship as a result of caregiving (70%), although 15% of caregivers reported a high degree of financial hardship (based on a self-reported rating of 4 or 5 on a scale of 1 to 5). Caregivers supporting their own child, regardless of the child's age, were more likely to report financial hardship (37%) than other caregivers (11%).[17]

Employer Costs

Businesses experience increased costs related to caregiving through a combination of a) increased health care costs due to poorer health among caregivers, b) fewer work hours by caregivers due to absenteeism, and c) the replacement cost for workers who leave their jobs due to caregiving responsibilities. A recent study of employees who were caregivers for an older adult found that these caregivers had higher rates of diabetes, high cholesterol, hypertension, and heart disease than non-caregiving employees. The study estimated these additional health issues cost employers $13.4 billion per year.[18] A 2006 report on the effect of caregiving for older adults on productivity estimated annual

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[15] AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, November 2008

[16] *Ibid.*

[17] *Ibid.*

[18] Albert, Steven M.; Schulz, Richard; and Colombi, Alberto *The MetLife Study of Working Caregivers and Employer Health Care Costs: New Insights and Innovations for Reducing Health Care Costs for Employers* MetLife Mature Market Institute, National Alliance for Caregiving, and University of Pittsburgh Institute on Aging: February 2010

employer costs of $17.1 billion per year from reduced staff time, workday interruptions, unpaid leave, replacement costs for people who left the workforce, and other costs.[19]

Information Needs

Most caregivers in 2009 reported needing more help or information (78%). Common information needs that caregivers identified include:

- Keeping the person receiving support safe
- Managing physical/emotional stress
- Easy activities to do with the person receiving care
- Finding time for oneself (more common for caregivers of children)
- Balancing work/family responsibilities (more common for caregivers of children)
- Talking to doctors and other professionals
- Making end of life decisions[20]

Caregivers for children and adults reported a few differences in information needs. Caregivers of children with special health care needs were more likely to need information about managing stress, work and family balance, finding time for his or her self, and managing challenging behaviors. Caregivers for adults were more likely to report needing assistance finding providers such as home care agencies, assisted living facilities, and nursing facilities.[21]

Iowa Initiatives for Informal Caregivers

Iowa offers a variety of resources to informal caregivers through information and referral services, respite, caregiver training, support groups, and direct financial assistance. The resources below describe direct assistance to caregivers. In addition, the paid services for older adults with functional impairments and people with disabilities described throughout the Iowa State Profile Tool are often provided to people who are receiving informal care, which in turn assist caregivers indirectly.

Information and Referral

Iowa has several initiatives to improve information and assistance, such as *LifeLong Links*, Iowa COMPASS and Iowa 2-1-1. *LifeLong Links* is an online Web portal which provides access to numerous resources for older adults, people with disabilities, and their caregivers. Through *LifeLong Links*, caregivers can access long term care planning tools, an online application for service programs managed by the Iowa Department of Human Services, and information and referral sites such as Iowa COMPASS and Iowa 2-1-1. The information and referral sites help caregivers identify programs and support services by county. Iowa COMPASS specializes in information and assistance regarding supports for children and adults with disabilities. Iowa 2-1-1 provides information regarding a variety of human services, including long-term

[19] MetLife Mature Market Institute and National Alliance for Caregiving *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Businesses* July 2006
[20] National Alliance for Caregiving and AARP *Caregiving in the U.S. 2009* November 2009
[21] National Alliance for Caregiving and AARP *Caregivers for Children: A Focused Look at Those Caring for a Child with Special Needs Under the Age of 18* November 2009

supports. As noted in the Iowa State Profile Tool, *LifeLong Links* and Iowa COMPASS have been funded in part by Aging and Disability Resource Center grants by the U.S. Department of Health and Human Services. Funding to sustain these initiatives is uncertain.

Iowa Family Caregiver Support Program

Iowa's 13 Area Agencies on Aging (AAA) administer the Iowa Family Caregiver Program. Through this program, funded primarily through the National Family Caregiver Support Program, family caregivers can receive information and referral services, respite, counseling services, caregiver training and modest one-time grants for supplemental services. Family Caregiver Specialists are available at each AAA to help caregivers identify needed services and supports, and to assist in navigating the service delivery system.

The Family Caregiver Program also operates a toll-free hotline (1-866-468-7887) for older Iowans and their families and caregivers. The hotline is staffed by the Iowa Association of Area Agencies on Aging (I4A) and provides an answering service for after-hours, weekends and holidays. In State Fiscal Year 09-10, nearly 450 older Iowans received assistance through the hotline.[22]

Respite Services

Several public services programs include respite services. Almost all Medicaid Home and Community-Based Services Waivers offer respite services to enable unpaid caregivers to take regular breaks from caregiving (the exception is the waiver for people with physical disabilities). More than 4,000 Iowans received respite services from these waivers in State Fiscal Year (SFY) 2009, with total expenditures of $24.8 million.[23]

Individuals with mental illness and/or developmental disabilities may receive respite services through county mental health and developmental disabilities services that are funded by a combination of state and county funds. Over 1,200 people received respite services in these programs during SFY 2009,[24] with total expenditures of $1.1 million.[25]

Grant Programs

Iowa's Department of Human Services offers two grant programs to help low-income families of children with disabilities purchase necessary services: the Family Support Subsidy (FSS) and Children-at-Home (CAH) programs. FSS is available throughout the year in monthly payments. During SFY 2009, FSS served 354 families with expenditures totaling $1,508,222.[26] Roughly 70% of families receiving FSS also receive Medicaid HCBS waiver services.[27] The CAH program is usually available for a shorter

[22] Data provided by Iowa Association of Area Agencies on Aging in August 2010
[23] Data provided by Iowa Department of Human Services, Iowa Medicaid Enterprise in July and August 2010
[24] Iowa Department of Human Services Mental Health and Disability Services Division "Statewide - Persons Served by Age Group, Population Group, and Service: FY 2009" January 21, 2010
[25] Iowa Department of Human Services Mental Health and Disability Services Division "Statewide - Expenditures by Service and Disability: FY 2009" January 4, 2010
[26] Data provided by Iowa Department of Human Services in June 2010
[27] Iowa Department of Human Services *Offer #401-HHS-010: Children with Disabilities* 2010

period of time than the FSS (often, one-time only).[28] In SFY 2009, 600 families were served under CAH, with total expenditures of $383,000.[29]

[28] *Ibid.*
[29] Data provided by Iowa Department of Human Services in June 2010

Addendum to the Iowa State Profile Tool: Section 2: Direct Care Workers

Direct care workers (DCWs) provide daily living support to older adults with functional impairments and people with disabilities. DCWs provide roughly 70-80% of paid long-term care in the United States.[1] This section presents information on the number of DCWs in the United States and in Iowa and their characteristics. The section then presents challenges faced by DCWs. It concludes with a summary of Iowa initiatives to address the challenges and improve the direct care workforce.

Prevalence of Direct Care Workers

Table 2.1 below displays an estimate of DCWs, as a proportion of state population, based on data from the U.S. Bureau of Labor Services (BLS). This estimate is based on the definition of DCWs in Section 5002 of the Patient Protection and Affordable Care Act. This definition, the first definition of DCWs in United States law,[2] includes four BLS job categories that are explained below:

- Nursing Assistants: people who assist people with activities of daily living and clinical tasks such as range-of-motion exercises and blood pressure readings, and who work primarily in nursing facilities and other residential settings.
- Home Health Aides: people who provide similar assistance to nursing aides, but in private homes or other community settings.
- Personal Care Aides: people who provide assistance with activities of daily living and routine household tasks. This category includes direct support workers for people with developmental disabilities.
- Psychiatric Aides: people who assist people with serious mental illness under the direction of medical staff.[3]

According to the most recent data available (May 2009), there were 3.1 million DCWs nationwide and 36,800 DCWs in Iowa.[4] Jobs in Iowa's direct care workforce comprised 2.5% of Iowa's total employment during that month.[5] These estimates likely understate the number of DCWs, because many providers of participant-directed services are not included.[6]

As a proportion of state population, Iowa has 20% more DCWs than the national average because of a higher number of nursing assistants. The relatively high number of nursing assistants likely reflects Iowa's relatively high number of nursing facility beds, as described in the Iowa State Profile section on Services for Older Adults.

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[1] Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010
[2] Paraprofessional Healthcare Institute "Federal Statutory Definition of Direct-Care Workforce Incorporates New DOL Job Classifications" April 1, 2010
[3] Paraprofessional Healthcare Institute "SOC for Direct-Care Worker Occupational Titles, 2000 and 2010 Compared" April 1, 2010
[4] U.S. Bureau of Labor Statistics *Occupational and Employment Statistics (OES) Estimates for May 2009* April 6, 2010
[5] Thomson Reuters analysis of data from U.S. Bureau of Labor Statistics *Occupational and Employment Statistics (OES) Estimates for May 2009* April 6, 2010 and Iowa Workforce Development *Iowa Labor Market Information: Nonfarm Employment in Iowa Summary Statewide (seasonally adjusted)* Accessed online September 2010
[6] Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010

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Table 2.1: Number of Direct Care Workers per 100,000 Population, May 2009

	Nursing Assistants	Home Health Aides	Personal and Home Care Aides	Psychiatric Aides	*Total*
Iowa	705	353	144	21	1,223
United States	468	311	205	20	1,005

Sources:
U.S. Bureau of Labor Statistics *Occupational and Employment Statistics (OES) Estimates for May 2009* April 6, 2010. Data are benchmarked to an average of May 2009 and November 2008 employment levels.

U.S. Census Bureau "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2009" June 2010

Direct Care Worker Characteristics

The Paraprofessional Healthcare Institute, a national technical assistance organization with expertise in direct care workforce issues, analyzed 2008 data from BLS employment statistics and the 2009 Annual Social and Economic Supplement to the U.S. Census Bureau's Current Population Survey. We use data from this analysis to describe several characteristics of DCWs.[7] Information specific to Iowa's DCWs are included where data are available.

Gender

Most DCWs were women in 2008 (90%).[8]

Age

DCWs were more likely to be age 55 or older (22%) than other women in the workforce (18%) in 2008. DCWs were less likely to be age 35 – 44 (20%) than all female workers (22%).[9]

Education

A majority of 2008 DCWs (59%) had a high school education or less.[10]

Race and Ethnicity

DCWs were more likely to be African-American and Hispanic than other women of typical working age in 2008. The proportion of DCWs who were African-American (28%) was twice the proportion of all women age 20 – 64 (14%).[11] DCWs were slightly more

[7] We included data from two fact sheets: Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010 and Paraprofessional Healthcare Institute *Older Direct Care Workers: Key Facts and Trends* April 2010
[8] Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010
[9] Paraprofessional Healthcare Institute *Older Direct Care Workers: Key Facts and Trends* April 2010
[10] Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010
[11] U.S. Census Bureau "Table 1. Annual Estimates of the Resident Population by Sex and Five-Year Age Groups for the United States: April 1, 2000 to July 1, 2009" June 2010 and U.S. Census Bureau "Table 4.

likely to be Hispanic. Sixteen percent of DCWs were Hispanic compared to 14% of women age 20 – 64.[12]

Employment Status

While a majority of DCWs worked full-time, 43% of DCWs in the nation worked part-time at least for part of 2008.[13] From 2005 – 2007, 51% of DCWs in Iowa were employed part-time.[14]

Wages

In both Iowa and the United States, DCW wages are lower than the median wage for all workers. Table 2.2 shows median hourly wage information for both the United States and Iowa. Except for psychiatric aides in Iowa, the median hourly wages for DCWs were at least 20% below the median wage for all workers.[15]

Table 2.2: Median Hourly Wages for Direct Care Workers and All Workers, May 2009

	Nursing Assistants	Home Health Aides	Personal Care Aides	Psychiatric Aides	*All Workers*
Iowa	$11.29	$10.37	$9.48	$14.02	$14.40
United States	$11.56	$9.85	$9.46	$12.33	$15.95

Source: U.S. Bureau of Labor Statistics *Occupational and Employment Statistics (OES) Estimates for May 2009* April 6, 2010. OES data are benchmarked to an average of May 2009 and November 2008 employment levels.

Challenges for Direct Care Workers

The rest of this section describes some challenges faced by DCWs that can lead them to pursue other careers. These challenges contribute to the difficulty providers have in recruiting and retaining DCWs. Although comprehensive and precise data regarding turnover and vacancies are unavailable, direct care work is a profession widely characterized by unfilled positions and high turnover.[16] While current jobs often are not filled, demand for DCWs is expected to rise as the population ages. Nationally, an estimated 4.3 million DCWs will be needed by 2018, an increase of more than 1.1 million jobs.

Annual Estimates of the Black of African-American Alone or in Combination Resident Population by Sex and Age for the United States: April 1, 2000 to July 1, 2009" June 2010

[12] U.S. Census Bureau "Table 1. Annual Estimates of the Resident Population by Sex and Five-Year Age Groups for the United States: April 1, 2000 to July 1, 2009" June 2010 and U.S. Census Bureau "Table 4. Annual Estimates of the Hispanic Resident Population by Sex and Age for the United States: April 1, 2000 to July 1, 2009" June 2010

[13] Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010

[14] Paraprofessional Healthcare Institute *State Facts: Iowa's Direct Care Workforce* July 2009

[15] U.S. Bureau of Labor Statistics *Occupational and Employment Statistics (OES) Estimates for May 2009* April 6, 2010

[16] See, for example, Edelstein, Steven and Seavey, Dorie *The Need for Monitoring the Long-Term Care Direct Service Workforce and Recommendations for Data Collection* February 2009 and Institute of Medicine, Committee on the Future Health Care Workforce for Older Americans *Retooling for an Aging America: Building the Health Care Workforce* 2008

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Lack of Health Insurance

In 2008, one of every four DCWs in the U.S. (26%) did not have health insurance. Only 53% of DCWs had coverage through an employer, compared to roughly 66% of Americans under age 65.[17] In Iowa, 24% of DCWs were uninsured from 2005 through 2007, while 54% of DCWs received employer-based coverage.[18]

Low Income

Nationally, DCWs earned an average of $17,000 in 2008, less than half the median worker's income of $35,400. This lower income is caused by a combination of lower-than-average wages and the high percentage of DCWs who work part-time. Many DCWs with low income qualify for public benefits. Two of every five DCWs (41%) received at least one public benefit such as Medicaid, food support (previously food stamps), or housing assistance.[19] Forty percent of Iowa DCWs received at least one public benefit from 2005 through 2007.[20]

Lack of Training

Many people consider training standards for DCWs to be inadequate, especially for supporting people with complex needs. There are national standards for Medicare-certified nursing facilities and home health agencies for both initial training and continuing education each year. There are no national standards for other DCWs.[21] State standards for different settings vary greatly in Iowa, as they do in most states. In addition to the time spent in training, the content of training and its effectiveness is also important to prepare people for direct care work. Effective preparation in initial training can lead to greater DCW retention.[22]

Lack of Advancement Opportunities

DCW positions often do not provide opportunities for advancement. Most positions do not offer opportunities to increase responsibility or to move to other health or long-term care professions with relative ease. However, several providers have implemented advancement opportunities such as career ladders or peer mentoring, which have successfully improved DCW retention.[23]

Iowa Initiatives for Direct Care Workers

The three initiatives described below can improve DCW training, recruitment, and/or retention by addressing the challenges identified above.

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[17] Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010
[18] Paraprofessional Healthcare Institute *State Facts: Iowa's Direct Care Workforce* July 2009
[19] Paraprofessional Healthcare Institute *Who Are Direct-Care Workers?* February 2010
[20] Paraprofessional Healthcare Institute *State Facts: Iowa's Direct Care Workforce* July 2009
[21] Institute of Medicine, Committee on the Future Health Care Workforce for Older Americans *Retooling for an Aging America: Building the Health Care Workforce* 2008
[22] Paraprofessional Healthcare Institute "Workforce Tools: The Right Start" Winter 2004
[23] Institute for the Future of Aging Services *Direct Care Worker Retention: Strategies for Success* January 2010

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Iowa Direct Care Worker Advisory Council

The Iowa Direct Care Worker Advisory Council was established in 2008 by the Iowa General Assembly and advises the Iowa Department of Public Health (IDPH) on regulation and certification of DCWs. The DCW Advisory Council has worked toward developing statewide training and certification standards for DCWs, building on previous work from similar workgroups such as the Direct Care Worker Task Force and the advisory group for Iowa's Better Jobs Better Care demonstration.

In the 2010 legislative session, the General Assembly set a goal to establish a certification board of DCWs by July 1, 2014, subject to availability of funds to establish and maintain the board. To work toward this goal, the legislation directed the Advisory Council to submit a report by March 1, 2012 (with an interim report on March 1, 2011). The interim report must:

- Document the size of the direct care workforce
- Identify the information system requirements of a DCW credentialing system including development and maintenance costs
- Report the results of pilot tests of training or curricula based on previous DCW Advisory Council recommendations
- Describes the development of an outreach campaign to enhance professionalism of the direct care workforce
- Make recommendations regarding the membership of the board of DCWs
- Estimate the costs and financing methods of the credentialing system and provide recommendations regarding this system

The Advisory Council has addressed some critical issues already, including development of a curriculum and a definition of DCW. For the latter, the Advisory Council chose to define DCW broadly to include many categories of workers who support people with disabilities and older adults with functional impairments. A curriculum subcommittee has developed a set of core competencies that would apply to all DCW and is identifying models from national sources for additional competencies. The IDPH has identified Federal grant opportunities to help fund the pilot. IDPH applied for a grant for which states were eligible, and a consortium of Iowa community colleges applied for a grant available to educational institutions.

An important aspect of the Advisory Council (and the Direct Worker Task Force which preceded it) has been the inclusion of DCWs, as well as employers and educational institutions. In addition, over the past two years the Advisory Council has conducted focus groups with people with disabilities and their family members to obtain their input.

Direct Care Worker Training under the Money Follows the Person Demonstration

As part of Iowa's Money Follows the Person Demonstration, the Iowa Department of Human Services, Iowa Medicaid Enterprise (IME) is testing the use of Web-based training modules developed by the College of Direct Supports (CDS) for people moving from intermediate care facilities for people with mental retardation (ICF/MR) and their parents, guardians, and providers. Training topics include community inclusion, cultural

competence, direct support professionalism, person-centered planning and supports, and individual rights and choice. The CDS training modules are developed by the University of Minnesota's Research and Training Center on Community Living. Over 30 states use the CDS training programs, which are tailored to each state's unique service delivery system and needs. Currently, 35 different providers or agencies representing 629 individual learners are participating in CDS.[24]

The University of Iowa's Center for Disabilities and Development acts as the statewide administrator of the training, a role that is funded by MFP. A formal evaluation of the program has not yet been completed. Anecdotally, some providers have reported decreases in critical incidents – events that cause harm to intellectual disabilities (ID) waiver participants or have the potential to cause harm – since their staff engaged in the training. Other providers have found the training to be an effective recruitment tool. People have approached these providers for employment after hearing about the valuable training from the provider's employees.

Consumer Directed Attendant Care

Many people who use participant-directed services choose to hire friends or family to provide their support, which brings new people into the field of direct care work. All of Iowa's Medicaid HCBS Waivers offer participant-directed services – called Consumer Directed Attendant Care – except for a waiver for children with a serious emotional disturbance. Workers in this program provide a variety of skilled and unskilled services to Iowans in their homes. As of June 2009, 3,671 individuals were paid to provide Consumer Directed Attendant Care. Most of these workers (87%) were employed less than full-time, with only 45% working 20 hours or more per week.[25]

[24] Data provided by the University of Iowa Center for Disabilities and Development in August 2010
[25] Thomson Reuters analysis of data provided by the Iowa Medicaid Enterprise in February 2010

Addendum to the Iowa State Profile Tool: Section 3: Supports for People with Alzheimer's Disease and Related Dementias

Dementia is a "loss or decline in memory and other cognitive abilities . . . severe enough to interfere with daily life."[1] Dementia is a common functional impairment that leads a person to need long-term care and affects more than half of Iowans in nursing facilities.[2] Alzheimer's disease is the most common type of dementia, accounting for 60 – 80% of cases. Alzheimer's disease symptoms range a gradual, increasing difficulty in remembering new information to disorientation and an inability to perform activities of daily living that, in the end stages, requires 24-hour-care. There is no cure for Alzheimer's disease, although a few medications have been found to slow the worsening of symptoms in about half the people who take them.[3]

This section presents information on the number of people with Alzheimer's disease and related dementias in the United States and in Iowa, and presents national data regarding the characteristics of people with dementia. It concludes with a summary of Iowa initiatives to improve support for people with dementia. Unlike other sections of this addendum, this section does not contain a separate description of challenges for people with dementia. The greatest challenge people with Alzheimer's disease and related dementias face is the condition itself – the decline of cognitive function that eventually affects all aspects of daily life.

Prevalence

A 2010 Alzheimer's Association report estimates there are 5.3 million Americans with Alzheimer's disease as of this year, including 69,000 Iowans age 65 or older with Alzheimer's.[4] We estimate an additional 7,000 age 55 to 64 have dementia, for a total of 76,000 people.[5] Alzheimer's disease is the 7th highest cause of death nationally, and the 5th highest in Iowa. In Iowa, nearly 5% of deaths in 2008 were caused by Alzheimer's disease.[6]

Characteristics of People with Dementia

The Alzheimer's Association report and other sources provide additional information regarding the characteristics of people in the U.S. with Alzheimer's and related dementias, which is summarized below.

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[1] Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures* 2010
[2] Centers for Medicare & Medicaid Services *MDS Active Resident Reports* Data from questions I1q and I1u on the MDS 2.0 form as of the first quarter of 2010
[3] Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures* 2010
[4] Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures* 2010
[5] This estimate is based on a Thomson Reuters analysis of data from the 2000 U.S. Health and Retirement Study. This study only included people age 55 or older, and showed 2% of people ages 55 to 64 had a cognitive impairment serious enough to be disabling. We applied this percentage to Iowa's 2009 population aged 55 to 64 to estimate 7,000 people with early onset dementia.
[6] U.S. National Center for Health Statistics *Deaths: Final Data for 2006* National Vital Statistics Reports. Volume 57, Number 14. April 17, 2009.

Addendum to the Iowa State Profile Tool: Section 3: Supports for People with Alzheimer's Disease and Related Dementias

Age

Although development of Alzheimer's and other dementias is not a normal part of aging, the prevalence of these conditions increases with age. Alzheimer's disease afflicts 5.1 million people age 65 or older, which is 13% of the U.S. population in that age cohort.[7] In contrast, 500,000 people under age 65 have early onset Alzheimer's and other dementias, which is approximately 1.5% of adults age 55 to 64.[8]

Gender

A majority of older adults with Alzheimer's disease and related dementias are women. A study of people age 71 or older found 16% of women and 11% of men had dementia. However, the high number of women with dementia is largely explained by women's longer life expectancy. Studies that focus on age of onset have found no significant difference based on gender.[9]

Rural Residency

Rural areas face particular challenges in serving people with Alzheimer's and dementia. First, prevalence of these conditions is likely higher because 1) people who lived in a rural area as a child are at a greater risk of developing dementia,[10] and 2) rural areas have a greater proportion of older adults than urban areas. Census data show that 15.6% of those living in rural Iowa are age 65 and older compared to 14.1% of those living in urban areas.[11] In addition, rural older adults are more likely to rate their health as "fair or poor" compared to their counterparts in metropolitan areas.[12] Rural individuals also may face greater difficulty in accessing health and long-term care services due to limited availability of providers and services and transportation barriers.

Other Social and Economic Factors

The Alzheimer's Association report identified several social and economic characteristics that are associated with a higher risk of developing dementia. Individuals with each of the following characteristics are at greater risk of developing dementia:

- People with fewer years of education
- People with lower income

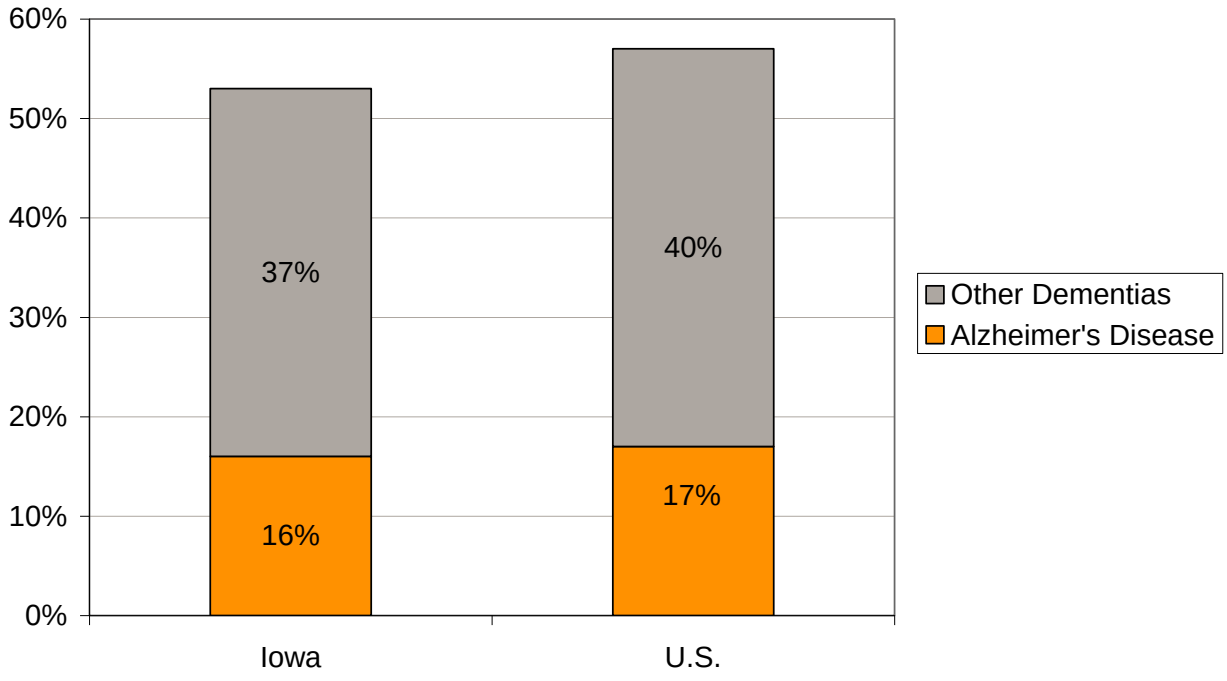
[7] Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures* 2010
[8] Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures* 2010 and U.S. Census Bureau "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2008" May 14, 2009. Alzheimer's Disease can affect people under age 55, but we use population data for the age 55 – 64 cohort to be consistent with the estimate of early onset Alzheimer's in Iowa on the previous page.
[9] Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures* 2010
[10] *Ibid.*
[11] Thomson Reuters analysis of U.S. Census American Community Survey 3-Year Estimates (2006-2008). Table B01001 Sex By Age (by geographical components)
[12] Coburn, A. F. "Rural Long-Term Care: What Do We Need To Know To Improve Policy and Programs?" *The Journal of Rural Health*. Volume 18, Number 5. June 28, 2008

- African-American individuals
- Hispanic individuals

Nursing Facility Residency

People with Alzheimer's disease and other dementias comprise a majority of nursing home residents. According to Minimum Data Set assessment data for the first quarter of 2010 (January – March), 16% of Iowa nursing facility residents have Alzheimer's disease and over 37% have other dementias. Both rates are slightly lower than the national average (see Chart 3.1).[13] Approximately 13,000 of the 25,000 Iowa nursing facility residents had dementia. This is 17% of the estimated 76,000 Iowa residents with dementia.

Chart 3.1: Prevalence of Alzheimer's Disease and Related Dementias Among Nursing Facility Residents, Iowa and U.S., 1st Quarter 2010



Source: Centers for Medicare & Medicaid Services *MDS Active Resident Reports* Data from questions I1q and I1u on the MDS 2.0 form as of the first quarter of 2010

Health Care Costs

According to an analysis of 2004 data for people age 65 or older, health and long-term care costs per person with dementia ($33,007) were three times higher than spending

[13] Centers for Medicare & Medicaid Services *MDS Active Resident Reports* Data from questions I1q and I1u on the MDS 2.0 form as of the first quarter of 2010

for people who did not have dementia ($10,603). Most of these increased costs were covered by Medicare, Medicaid, or other insurance. Out-of-pocket per capita costs were 29% higher for people with Alzheimer's/dementia compared to those without the conditions. Medicaid costs were significantly higher, likely reflecting greater use of nursing facility care. For people eligible for both Medicare and Medicaid (dual eligibles), Medicaid per-capita costs for older adults with dementia were nine times higher than Medicaid costs for other dual eligibles.[14]

Iowa Initiatives Related to Alzheimer's Disease and Related Dementias

Iowa has taken several steps in recent years to improve supports for people with dementia. This section does not identify resources available for Iowans with Alzheimer's and other dementias and their caregivers, which have been described in the Section 4 of the Iowa State Profile Tool (Services for Older Adults) and in Section 1 of this Addendum.

Alzheimer's Disease Task Force

The Iowa legislature authorized an Alzheimer's Disease Task Force in 2007 to:

- Assess the current and future impact of Alzheimer's disease and dementia on Iowans
- Identify services and resources available to persons with these diseases and their caregivers
- Develop a state strategy to address identified issues and concerns

In 2008, the Task Force issued a report with 22 recommendations relating to a variety of topics: training and education of direct care workers and other caregivers, community-based support services, awareness about dementias and early detection tools and others.

Iowa Dementia Education Project

In 2008, the Iowa General Assembly passed legislation to expand and improve training and education of people providing care for individuals with Alzheimer's and other dementias. The Iowa Department on Aging contracted with the Alzheimer's Association, Greater Iowa Chapter, to develop a curriculum and dissemination plan. The contractor created a Dementia Education Task Force, which coordinated its work with the Direct Care Worker Advisory Council described in Section 2 of this addendum. The Dementia Education Task Force delivered a standard curriculum model for dementia education in May 2010 and provided recommendations for certifying the curriculum and trainers, creating administrative rules, and disseminating information about training standards.

Although the legislation was broad in its inclusion of many types of audiences for the training (far beyond direct care workers and unpaid caregivers), the limited amount of

[14] Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures* 2010

funding for the effort necessitated narrowing the scope to direct care workers.[15] The contractor recommended that the standard training curriculum should be 16 hours which must be completed within 30 days of initial employment. After receiving initial training, direct care workers would be required to receive eight hours of continuing education annually. The curriculum would include the following competencies: understanding dementia, communication, person-centered/directed care, understanding behavioral symptoms, unique aspects of daily living, meaningful relationships and social engagement, ethics of caregiving and understanding and managing stress. The contractor recommends using a variety of methods of instruction to optimize access and effectiveness.

Designation for Care Settings and Programs

Iowa Administrative Code establishes distinct regulations for care and service settings which are designated for people with "chronic confusion or dementing illness" (CCDI). The CCDI regulations apply to nursing facilities, assisted living facilities, elder group homes, and adult day programs, all of which can request CCDI designation. The regulations outline staff training and other requirements which are specific to supporting people with dementia. For example, staff working in a CCDI nursing facility or CCDI-designated unit of the facility must have at least six hours of training specific to serving residents with dementia within 30 days of their assignment to the facility or unit.[16] For staff working in elder group homes, assisted living programs and adult day services, the training requirement is eight hours.[17] The Iowa Department of Inspections and Appeals (DIA) determines CCDI designation, as well as licensure of these facilities and programs. In recent years, the Department of Inspections and Appeals has focused on implementing dementia-specific training to its nursing facility and assisted living facility surveyors.

[15] Iowa Dementia Education Project Final Report *Alzheimer's Disease and Other Dementias: Curriculum and Dissemination Plan* Submitted by Alzheimer's Association, Greater Iowa Chapter, to the Iowa Department on Aging. June 30, 2010
[16] Iowa Administrative Code [481], 58.54(6)a
[17] Alzheimer's Association and HealthCare Interactive "State of Iowa Dementia Training Requirements and the CARES™ Online Dementia Care Training Program" Updated March 8, 2010